

SUMMARY OF DISCUSSION

NCBDDD External Partners Group Executive Committee Conference Call

Date: Monday, March 21, 2005; **Time:** 1:03-2:00 pm (EST)

Participants: *Jane Correia, National Birth Defects Prevention Network (NBDPN)
*Bob Delaney, Chief of Staff, Centers for Disease Control and Prevention (CDC)
*Julie Gerberding, Center for Disease Control and Prevention (CDC)
*George Jesien, Association of University Centers on Disabilities (AUCD)
*Alison Kelly, National Center on Birth Defects and Developmental Disabilities (NCBDDD)
*Barbara Kilbourne, National Center on Birth Defects and Developmental Disabilities (NCBDDD)
*Brad Perkins, Office on Innovation and Strategy (CDC) via Envision
*James Rimmer, National Center on Physical Activity & Disability (NCPAD)
*Clarke Ross, Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD)
*Jeremy Scott, Tourette Syndrome Association (TSA)
*Donald Shriber, Washington CDC Office (CDC)
*Donna Stroup, Coordinating Center on Health Promotion (CDC)
*Marina Weiss, March of Dimes
*Michelle Wilson, Office on Innovation and Strategy (CDC) via Envision
*Laurie Fletcher (AUCD)

Invited but Not Able to Attend:

*Serena Lowe, B&D Sagamore
*Lowell Sever, Past Chair of EPG

Agenda

Dr. Stroup began with a welcome and thank you to Dr. Gerberding for meeting with the EPG Executive Committee. Soon after, members of the EPG each went around and introduced themselves to Dr. Gerberding and gave a brief overview of the organizations that they represent. It was also noted that Michelle Wilson, Brad Perkins, and Bob Delaney are participating via Envision from Atlanta, GA.

Meeting with Dr. Gerberding

George began the meeting by stating that it was the hope of the EPG that a mutually beneficial relationship be established with Dr. Gerberding. The EPG wants to make itself available to assist the CDC in its reorganization efforts, as well as inform CDC of the importance of the constituencies represented by the EPG.

Ms. Marina Weiss from the March of Dimes was asked to give a brief background of the NCBDDD and the EPG. The NCBDDD was authorized as part of the Children's Health Act of

2000 and reauthorized in 2003 by unanimous votes in both houses of Congress. Many members of the coalition that worked on the legislation that initiated the NCBDDD make up the existing EPG.

The EPG is now very interested in seeing how it can be of assistance and participate in the implementation of the CDC's Future's Initiative.

- Dr. Gerberding posed the question of what the EPG would define "success" to be. She said that it did not necessarily have to be quantifiable but rather conceptually (i.e., in terms of where we would like to be in ten years.) CDC is trying to move forward in a more goals oriented manner and would like the EPG to think about what it would consider successful outcomes in their future relationship with CDC.

Overall, members of the EPG executive committee expressed hope that the interface between public health and disability continues to be a major focus in CDC's new restructuring plan and become fully integrated into their planning and implementation processes. The goal is that as public health policy is developed and implemented, supports and services, prevention of birth defects, developmental disabilities and secondary conditions, and health promotion for persons with disabilities become important and integral parts of the public policy development process. The disability community, on its part, will also need to view how their needs and priorities fit into and affect the overall population-based public health agenda. It is the hope of the EPG that a trust level develops between the organizations that represent people with disabilities and those who work on their behalf with their federal partners. The EPG wants to ensure that disability issues have a "seat at the decision making and priority setting table," and view this opportunity as a way to continue a meaningful dialogue to ensure that we are effectively moving in that direction.

Questions asked by EPG Members (EPG) and Answers or questions provided by Dr. Gerberding (JLG)

- JLG: What would it take to reassure people that we mean *everyone* even if we don't say everyone?
- EPG: The problem is that some disabilities have different stigmas in terms of societal acceptance (i.e. Tourette Syndrome). Putting things in general terms does not always capture everyone in the disability community. There needs to be a balance between the needs of specific constituencies and the general disability community.
 - EPG The inclusive message is a great way to address the disability organizations. You rarely see people with disabilities engaged to the degree they could be in their communities and natural environments.
 - JLG commented on a survey conducted at CDC where persons with disabilities were the least satisfied with their experience at CDC and Dr. Cordero has made some recommendations on how to change this. Dr. Gerberding accepts responsibility for this dissatisfaction and is working to change it. She stated that we need to provide an example and make the environment comfortable and hire people with disabilities within CDC.
 - JLG: One philosophy of the Future's Initiative is that we want a CDC where the *whole is greater than its parts*. We can have great individual centers but they are stronger and more effective because of the other parts of the CDC. CDC is trying

to make itself into more of a hub with individual centers who work well with each other as well as with other federal agencies (i.e., Department of Education).

- **EPG:** The EPG is trying to do exactly this. The EPG is a hub of diverse organizations representing a broad spectrum of disability-related issues that brings together many interested parties into a united ‘whole.’
- **EPG:** There is a concern about the future of state-based surveillance – can you speak to that?
 - **JLG:** Surveillance is a fundamental function of CDC because it is how we account for reaching our goals. It will remain being as such, a foundational activity that is supported.
- **EPG:** We want to be able to do more, but we also want to have a more diverse group of people participating in these conversations. How do we reassure our constituency groups that this will be supported by CDC? How do you manage this and how do you get everyone moving in the same direction to achieve your objectives?
 - **JLG:** Agreeing on strategy is a good place to start and letting smart people determine the “what”. Networks evolve over time and require trust, knowledge and understanding. This is a ‘people’ thing. We need effective networks to successfully deal with the problems that public health and CDC is facing. However, continually broadening the community while maintaining open lines of communication is a difficult task.

EPG: Many of the EPG partners work with multiple federal agencies because of their interests, populations and funding sources. It is laudable to have you at the federal level ~~talking about and~~ working to collaborate across federal agencies. One of the great things about the EPG is that we have come together to move things forward, like the Children’s Health Act, and the mission of the NCBDDD and CDC overall. The naming of Barbara K. as a liaison to the EPG was an excellent decision and has created an exemplary relationship between the EPG and the NCBDDD. We also have experienced an extremely positive response from Drs. Stroup and Cordero. They have demonstrated their willingness and openness to listen as they have attended our meetings and supported the development of the EPG network.

As a point of interest you may like to know that the EPG reached out to some of the larger Chronic Groups to discuss possible areas of overlap and common interest and found that there were definitely some areas of possible future collaboration.

Questions

EPG: What is the role of the National Center Directors?

JLG: The Centers have not changed and are still the primary force for categorical science and program development and the primary ‘touch point’ for relevant stakeholder connectivity. The Centers will be as strong as they have always been. I would like to think of them as stronger as they extend their ~~ear~~ reach into collaborations that they might not have thought of previously. If our Centers are successful, you will have the science needed to address problems and the results to be able to show Congress for future funding and support. I believe that the best policies come from the best science. The difference is that by clustering some Centers together, we can, on a

very strategic level, work for greater connectivity and collaboration to enhance the output. The bottom line is that CDC's mission has grown greatly. CDC's investments have not. If we are going to ~~will~~ accomplish what is in our portfolio, we have to prioritize and use every single dollar as effectively as possible. We will hold Divisions harmless and want to drive FTEs and budgets up. We do this by cutting down superfluous costs (\$4 out of ever \$10 is used for indirects – too high). Not all Centers will have increased budgets and FTEs. As you look at the Centers in each Coordinating Center, there are twelve individual Centers across the board. In putting groups together, it was also helpful for allocating resources and leveraging strengths into Coordinating Centers, since there are not enough resources to develop twelve of everything. It is an issue of borrowed strength.

Dr. Gerberding emphasized that the program Centers such as NCBDDD are the core” of CDC activities and will not change. They are the main ‘touch point’ for the science.

Dr. Gerberding stated that existing programs would not receive reductions. Building administrative infrastructure for the Futures Initiative will not result in existing program funding being reduced.

Dr. Gerberding emphasized that she wanted to bring CDC programs to “scale” in order that such programs have “real impact.” She wants more than many small programs whose impact is limited. She wants true impact – impact on the nation’s health.

JLG: If we were in another time when we would see a sizeable increase in the CDC budget, trust is easier. One thing for sure is that we have let people off the hook too easily because we let people be satisfied with too little (\$100,000 here and there). If we had enough \$100,000 programs and people, we might be able to develop a program that we could be proud of. My desire is that one message is delivered to the Hill but that requires trust that **I** realize still needs to be developed.

EPG: A lot of the partners are concerned that they have worked hard to go up to the Hill to get funding for the NCBDDD or an individual program or area of research and now they are concerned with what will happen to these programs as a result of the reorganization. How will the Coordinating Center prioritize who gets funded and to what extent?

JLG: The line items of our budget are not going to change. The program lines are protected at the larger level but the programmatic decisions are still up to the individual Centers. The development of new programs would be up to the discretion of the individual Centers. The only difference is that we want to be aligning funding to goals. This will allow us to show performance and outcomes- *success sells*. We will be able to sell to consumers solid examples of success. For example, immunization did not start out as big of a program and grew as it showed success.

JLG: My primary area of focus is research. It is imperative that CDC works with NIH more closely. There are areas of research that NIH can not do, so CDC has to step up and conduct that research. I have two overall priority areas: public health research and building CDC’s infrastructure. We need lots more here. The purpose of such translation is to improve and

consistently use evidence-based practice – translating science to actual professional practice. This is a very important topic for many family and consumer groups.

EPG: Does this include translation research?

JLG: What I consider “research” is translating research into practice, informatics, dissemination, and communication.

EPG: How is the life stage concept going to work with the states and programs that are already working with CDC?

JLG: It depends on how you touch your constituents in your states. Immunization is now a life stage program that touches on all five life stages. States often bring together programs that are more holistic. HRSA is a major player in this program.

EPG: The National Birth Defects Prevention Network has been very effective. Cara Mai has done a great job as a CDC liaison with the National Birth Defects Prevention Network. If what happens in the Coordinating Center could model itself on what goes on for the NBDPN, we could eliminate a lot of replication.

JLG: Is anyone here engaged in the research development agenda? How did that go?

EPG: Okay and if I had to grade it a B, B-. There were a lot of comments with having only one category for the 50+ and older age group. We thought that there could actually be more categories for older adults – the needs of 60-year olds are quite different from those in their 80’s. We want to see how it goes from here and how it impacts research procedures and allocation of resources. We encourage you to keep soliciting public input and becoming more systematic. Maybe there should some more targeted areas for feedback in both the research and consumer areas. Also, adequate notice is important. It is important to give adequate notice so that organizations aren’t just sending a person to these meetings without giving adequate time to prepare responses on behalf of the organization.

EPG: We would like your ideas on how we could be helpful points of dissemination for CDC’s plans, future directions, etc and how we could serve as a “hand on the pulse” of what organizations and various constituencies are thinking and reacting to. This would provide CDC additional information during various stages of the Futures Initiative.

JLG: Help CDC get relevant stakeholder input in their priorities. We are going to need help thinking in a five year block of time rather than in a federal budget time frame. Pass questions forward so that there can be clarification. Let us know if there are concerns as there is a plethora of urban legend out there. A really helpful thing would be to articulate the doubt and positive aspects to be successful. The CDC needs some champions to help move the reorganization forward. The Centers need to know that their stakeholders are with the reorganization.

The EPG asked about the areas of resource allocation, maintenance of programs, research agenda, and decision-making.

Dr. Gerberding responded that she would like us to help drive programs with goal setting. EPG members emphasized the need for adequate advanced notice for discussing informed science-based input into CDC.

JLG: What are the most important things that we are concerned with?

EPG: -resource allocation (determination of prioritization)

-Maintenance of programs that we feel are critical to public health and disability

-Decision making issues and the process of setting priorities

-What is on the agenda

JLG: Those decisions will not be made by the executive committee or by me. The real issue is the goals team that is developing the priority actions. It is important that partners engage through the Centers. There will not be fewer dollars (most likely more) depending on how we can manage the development of CDC.

EPG: Where should we be in the input process?

JLG: We should be speaking to Drs. Cordero and Stroup. If you need to get in touch with me e-mail is effective. I read all of my e-mail. I may not respond to it, but I read it.

Next Steps

George thanked Dr. Gerberding for her willingness to meet with the EPG Executive Committee and for discussing important issues related to the CDC reorganization plan. He expressed a hope that this meeting will lead to continued open communications in the future. He went on to say that it is important for the EPG to help Drs. Jose, Stroup and Gerberding succeed because that means that the EPG succeeds as well. The goal of this meeting and future meetings is to harness our respective energies and resources and to focus our efforts so that we can move forward in the same direction.

Meeting adjourned at 2:17 pm.